

Reference Number:	502-08-DD
Title of Document:	Ethics Committees-Regional Centers
Date of Issue:	January 9, 2001
Effective Date:	January 9, 2001
Last Review Date:	April 15, 2007 (REVISED)
Date of Last Revision:	April 15, 2007
Applicability:	SCDDSN Regional Centers

I. Purpose

The South Carolina Department of Disabilities and Special Needs (the Department) recognizes the need to foster awareness and provide support for addressing ethical issues which arise in assisting individuals with disabilities. Each Regional Center will maintain an ethics committee, which will serve both the Regional Center and District Office. The ethics committee will be designed to function in three broad areas:

- (1) educational activities for consumers and staff;
- (2) consideration and discussion of ethical issues arising in the development and implementation of department policy; and
- (3) consideration, discussion and consultation of ethical issues which arise in care of individuals residing at the regional center or in the community.

The activities of the committee should establish a working basis that supports the interest and welfare of consumers, respects their autonomy and informed choices, prevents harm and promotes fairness for all consumers.

II. Policy

A. Composition and Functions

Historically, ethics committees have reflected the needs of hospitals and doctors in dealing with clinical dilemmas and policy issues involving level of care and intervention decisions. The Department has very limited ability to deliver hospital-style care. Many of the services provided by the Department involve programmatic decisions of day-to-day living choices. Thus, the Department endeavors to combine both medical and programmatic issues and address them with one regional ethics committee. The ethics committee will include representatives from both areas and use an interdisciplinary approach to problem solving. The three-fold functions of the ethics committee are as previously mentioned: education, policy review and case consultation.

1. Education

The educational component of the ethics committee is aimed first at its members, then at the staff and administrators, and finally to the consumers and their families. The ethics committee must educate its members regarding the programmatic and clinical obligations to their constituency, the rights and choices available to the consumers, the process of practical deliberation of ethical issues, the interplay of moral and legal issues, and the philosophy of the Department's best practice standards and various licensing/certification requirements. The ethics committee may recommend or develop educational programs for the staff and administration, i.e., informed consent and substitute consent. Additionally, the ethics committee may sponsor seminars and meetings with consumers and their families covering topics about personal choice and responsibility, end of life medical decisions or placement options.

2. Policy Review

The ethics committee is not a policy-making committee. At the request of the district director, facility administrator or upon referral by the chairperson of the committee, the ethics committee may review the ethical aspects of proposed policies or initiate suggestions for policy changes or additions with regard to ethical issues impacted by those policies.

3. Case Consultation

Case consultation is a method by which the ethics committee can serve as a sounding board, give advice or facilitate decisions regarding a specific issue of concern regarding one of the consumers served. Case consultation provides a method by which health care professionals, care givers, administrators, consumers and families can work through problems and make informed decisions. The ethics committee does not make decisions and acts only to make non-binding recommendations.

Referral of a situation to the ethics committee for case consultation can come from any regional center staff, family member or consumer. The district director can make referrals for case consultation for a consumer receiving services in a community setting. The ethics committee will determine which cases they will consult on.

B. Relations with the Human Rights Committee

A Human Rights Committee (HRC) is required by South Carolina Law [S.C. Code Ann. §44-26-70 (Supp. 1999)] and Medicaid regulations (TAG No. W261). Consequently, the Department has published a directive establishing the HRC, 535-02-DD. In accordance with the directive, certain issues must be reviewed by the HRC. These include, but not limited to, any restriction of personal freedoms or rights in an individual's program plan; any use of a restrictive or intrusive procedure in a behavior support plan or use of behavior control medication.

The HRC reviews policies and research proposals that may affect the rights of individuals receiving services. It receives notification on the use of emergency restraints and allegations of abuse. It also reviews the adequacy of informed consent by individuals or substitute consent givers for research, intrusive procedures or programs, and cases where the facility or executive director provides substitute consent. Grievances of consumers pertaining to programs, placement, and rights issues are also reviewed by the HRC.

As mentioned, many of the activities of the HRC are mandated. However, there are no specified issues that are required to be presented to the ethics committee. It is possible that the same situation may be presented to both committees. However, as a general rule, the ethics committee would typically not address those issues which are addressed by the human rights committee.

The potential overlap of the two committees may be confusing, but they are separate in their make-up, function and authority. The ethics committee helps professional staff determine the recommended course of treatment where moral issues are involved. In those cases that must be reviewed by the HRC, notwithstanding a previous review by the ethics committee, the HRC will determine if the recommended course of treatment violates any rights of the individual. Therein lies the basic distinction between the two committees.

C. Relations with Other Committees

The ethics committee is an internal committee of each region. It does not function as a forum to appeal programmatic, medical or administrative decisions, nor to air grievances from employees, consumers or families. It is not designed to be a steering committee or to set policy. Its functions are unique and limited to ethical considerations.

The ethics committee is encouraged to reach out and network with similar committees in the local community or within the State. The ethics committee may upon approval of the district director or designee invite experts in specific areas to advise, consult or educate the committee and others on ethical issues.

D. Membership

The ethics committee should be composed of individuals with the requisite degree of experience and training that would give them an understanding and sensitivity of ethical issues involved in providing quality services to individuals with disabilities. At least one member should be from the local community, not otherwise associated with the regional center. The ethics committee should reflect a cross-section of services: medical, nursing, direct care, social work, administration and other adjunct disciplines. The ethics committee size should be only so large as to provide an interdisciplinary approach to problem solving; yet, not so large as to hamper its ability to expeditiously address the often time-sensitive issues presented to the committee.

E. Ethics Committee Guidelines

Each ethics committee will maintain guidelines for the operation of the committee. At a minimum the guidelines should cover the following topics:

- Name, purpose and function. Guiding philosophy may also be addressed.
- Membership, appointment, terms, removal.
- Officers, chairperson, secretary, others, appointment, terms, removal.
- Meetings, regular, special called, agenda setting.
- Method for notifying staff, families, consumers of the availability of the ethics committee as a resource.
- Consensus method for consultations, quorum for action, proxy.
- Access to the ethics committee, i.e., how are issues (education, policy review, case consultation) going to come before the committee.
- Method of case consultation.
- Reporting committee advice, recommendations, and consultations; storage of records and reports.
- Confidentiality.

The Department recognizes that each region in developing its guidelines will reflect its different consumer population, disciplines and staff availability and unique regional needs/issues.

F. Confidentiality

The activities, meetings and records of case consultations conducted by the ethics committee are confidential and are fully protected by State law regarding confidentiality of client records. Further, it is the intent that all activities, meetings and records of the ethics committee receive confidential protection against any request for disclosure, not only as previously stated, but also because the committee's actions, meetings and records are only advisory in nature and designed for internal consumption to promote quality care. The ethics committee does not set standards of care or practice, nor does it judge whether any such standards have been met. The ethics committee meeting, activities and

records are closed to the public and not subject to disclosure under the State Freedom of Information Act. All persons participating in any meeting or activity of the ethics committee or having access to client records are bound by the rules and laws of confidentiality.

David A. Goodell
Associate State Director,
Operations
(Originator)

Stanley J. Butkus, Ph.D.
State Director
(Approved)

Kathi K. Lacy, Ph.D.
Associate State Director,
Policy